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Author Biography

Susan Stuntzner, PhD, is an Assistant Professor in the rehabilitation counseling profession at University of Texas – Rio Grande Valley. Prior to that she was at University of Idaho – Coeur d'Alene. She is also a Licensed Professional Counselor, a Certified Rehabilitation Counselor, a Nationally Certified Counselor, and a Distance Credentialed Counselor. She currently teaches students to become counselors, writes, and conducts research. Her research and writing interests include: psychosocial adaptation to disability, family coping following disability, forgiveness and spirituality, self-compassion, resiliency, mentorship of persons with disabilities, and development of coping strategies for persons with disabilities.

Dr. Stuntzner is the author of two other books. They are entitled, *Living with a Disability: Finding Peace Amidst the Storm* and *Reflections from the Past: Life Lessons for Better Living.* This past year, she also developed two interventions for persons with disabilities to help improve their coping and adaptation process. These works are entitled, *Stuntzner and Hartley's Life Enhancement Intervention: Developing Resiliency Skills Following Disability* and *Stuntzner's Forgiveness Intervention: Learning to Forgive Yourself and Others.* The life enhancement intervention has shown strong preliminary results in reducing anxiety and depression and increasing forgiveness and resiliency. It has also demonstrated promising results in altering phases of the adjustment to disability process. The forgiveness intervention is slated for initial pilot testing soon. Additional information about her work, books, or interventions is available on her website: http://therapeutic-healing-disability.com.

Prior to this time, Dr. Stuntzner worked in the Midwest providing mental health services to people with developmental disabilities and other co-morbid conditions. She is a graduate of University of Wisconsin – Madison where she obtained her PhD in rehabilitation psychology. Previously, Dr. Stuntzner practiced as a rehabilitation counseling professional in the Northwest.

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In writing this book, I would like to acknowledge and thank my family and friends for walking the journey of life with me. Because of their continued support and encouragement I have been given the gift of discovery and exploration as I found my way to this point-in-time. My parents, for whom I am grateful, have been instrumental in teaching me the importance of resiliency, endurance, hard work, and perseverance. Through these lessons, I learned more about myself and my ability to complete challenging tasks. In truth, I learned the importance of locating my voice and being willing to follow the path I am to pursue. I would also like to thank four close friends: Trish, Jacque, Kristen, and Karla who have been a key part of my more recent journey. Without their support, this book and the road to getting here would have been more difficult. Lastly, I am indebted to my Administrative Assistant, Julie Wasson, for taking the time to read and proof this and previous book manuscripts. Her editorial comments are very much appreciated and helped provide me with clarity in the midst of a vast but important topic.

FORWARD

Life following a disability can be challenging and confusing for many people. In the "*blink of an eye*," families may find their life drastically altered. The present and future may seem bleak at best. Feelings of shock, fear, anxiety, and anger may surface quite unexpectedly, as there is much to figure out. Questions regarding what to do, where to go, whom to ask may abound. More specifically, family members and loved ones may wonder, "How did we get here?" "Why did this happen?"

Some may think, "I should have known." "I should have prevented this." "If only she would have done what I told her to do."

Others may ponder, "How will I take care of my family member?" "How will we survive?" "What does life hold for us now?"

With so many questions and so few answers, families may feel lost, alone, and confused. They may be confronted with many difficult decisions as they try to sort out what life has in store for them in the days, months, and years ahead. Family members may feel as if they need to solve disability-associated problems in the life of their loved one and deal with the immediate situation at hand. Oftentimes, family members don't believe they have any right to feel their feelings or deal with the situation they now find themselves faced with because their life problems seem miniscule compared to those of their loved one. As this pattern of avoidance or not actively facing their feelings and thoughts continues, family members may set themselves up to harbor negative feelings or experience undesirable ways of existing and being rather than successfully accepting the situation and moving past it.

Successful coping and adaptation to life following a disability involves tending to the needs of the family member with a disability and the family. For many, the experience of disability is often focused solely on the family member with a disability. And, while this is certainly key and crucial for adaptation to disability to occur, the family and its needs are often overlooked. Oftentimes, the family inadvertently takes on the silent and necessary role of *crisis solver*, *information gatherer*, and *transition planner*. Family members find they must figure out how to: (a) keep the family together, (b) help oneself and others manage feelings and concerns associated with this unexpected change, and (c) provide stability to the family member with a disability and the family. This is particularly true when disability happens suddenly and unexpectedly.

For example, in situations where the experience of disability is quick and unforeseen, such as Traumatic Brain Injury (TBI) or spinal cord injury (SCI), much attention is focused on stabilization, followed by rehabilitation and information gathering, and hope of physical and/or mental improvement. At this point, rehabilitation specialists, occupational therapists, physical therapists, nurses, and other medical personnel are focused on the immediate needs of the person. During the stabilization process, needs and concerns of the family may *appear* secondary or nonexistent. In some cases, information or education about the specific disability may be given or minimal information about home planning and transition may be provided.

Regardless of how much information is conveyed, some families take advantage of what opportunity is provided and seek medical or disability-related information in an effort to learn what

they can about the disability. Families that are able to acquire information prior to leaving the safe walls of medical facilities may start deciphering their needs related to today and the future, thus reducing *the feeling of immediate crisis*. In many cases, family members become overwhelmed with the changes experienced and do not make time to acquire the necessary education and information. Following the transition from hospital to home, the family is often left on its own to '*figure it out*'. Family members are on their own to sort out their thoughts and feelings about the experience of disability and sometimes feel alone or unsupported. Quite unexpectedly they find themselves in a position of sorting out necessary and often unexpected situations and life roles.

Prior to integrating back into the community, foresight and planning must occur between medical personnel and the family for smoother transitions to occur. Planning for the transition home is essential for successful integration because once the family leaves the safe supports of the hospital or medical facility, easy access to medical and rehabilitation-related professionals decrease. Family members must then figure out how to get their needs met without the guidance of professionals at their fingertips.

As the realities of "*living life on life's terms*" following disability unfold, family members soon realize they are faced with many decisions and changes including: caregiving, advocacy, medical coordination, advocacy, and so forth. Initially, family members may take on these roles without much forethought due to necessity and concern for the family member with a disability. But, over time, individual family members may feel the pressure or strain of their new life and altered roles. Somewhere in this process, they may lose track of their family or relational roles (i.e., spouse, romantic partner, sibling) and lose sight of the other important elements of relating to another person. These forgotten roles and parts of life sometimes lead to negative feelings, such as *resentment* or *burnout*, which in turn affect the relationship between the family member with a disability and family members.

Coping with and life following a disability can be rather complex and confusing. Regardless of disability type (i.e., congenital, acquired, or age-related), family coping and adaptation following disability involves the necessity of sorting out the realities and complexities of living life well despite the change within the family. In essence, families and individual family members must sort out and make sense of their experience with the disability-related changes. Each family has its own process and reaction. Some families may be very supportive and do what they can to keep the family together. Other families may have difficulty integrating changes brought about by disability and become *overtaxed* by the changes in family functioning. Still, others find themselves someplace in-between the two extremes. In any of these situations, families must find a way to process, adapt, and move past the unexpected changes brought about because of disability.

In addition to the coping process experienced by the family, each person within the family has his or her own *process* and *reaction* to the changes brought on by disability. As mentioned earlier, some family members may believe they don't have time to deal with how they feel or what they believe about their loved one. Others may believe they don't have *the right* to get in touch with their inner self because their personal needs are *minimal* in comparison to those of their loved one. Still, others may simply view it as too painful to go there and turn back; thus, they are not even willing to consider the idea of self-exploration.

Families and individual family members must take time to sort through their feelings and reactions following their loved one's disability so that successful adaptation can occur. Family members not addressing their inner feelings, beliefs, and process run the risk of manifesting their reactions to disability-related changes in some other way. In essence, they face the possibility that their feelings or beliefs about disability and its meaning may come out sideways in a more hurtful way than desired, especially if their inner beliefs and feelings are *negative*. Unrecognized and unaddressed negative feelings also have the ability to influence the relationship between the family member with a disability and her familial relatives in undesirable ways. This is of concern because negative ways of relating not only become a source of strain for the persons involved but also a source of deep-seeded pain which may affect everyone's ability to function and live life well.

Disability, the experience of disability, and life following disability do not occur in isolation. Nor do the effects of disability only impact the family member with a disability - disability affects other family members too (Reichman, Corman, & Noonan, 2008). Further, the interaction between the coping abilities of both parties and changes brought about because of disability are thought to affect one another. This interaction process would make sense as any personal interaction between two or more people is affected by the relationship itself and by each person's perceptions of one another and personal well-being.

Because the process of coping and adaptation to disability affects the both the family member with a disability and family, it is an area worthy of exploration for both parties. The experience of disability and life following disability can be confusing and ambiguous for the family member with a disability. When we consider the needs of the family, the coping and adaptation process to disability and life following the disability can feel *overwhelming, isolating,* and *confusing* at best. This is partly related to the fact that many families do not get the resources or professional support they may need to make sense of their experience and feelings. Many families are also not supplied with the therapeutic or counseling sessions they need through their insurance companies. Therefore, many families are left on their own (just like the family member with a disability) to figure out how to move past this experience.

In my previous book, *Living with a Disability: Finding Peace Amidst the Storm*, I share some of my experiences of living with a visible condition which many 'onlookers' and strangers would coin a disability. Although I do not see myself in that way, I am well *aware* that many people outside my circle of friends and loved ones have a tendency to categorize, label, and judge me as just that - disabled - because the visibility of my situation is ambiguous to them and something they do not understand. Over the last 30 years, I have become acutely aware of other peoples' perceptions and erroneous beliefs. During this same time span, I have also observed and experienced the powerful influence family support can provide in strengthening and moving a person forward following the acquisition of a visible disability.

Outside of my own personal experiences, I have observed, professionally, the influence of family on the lives of persons with a disability who are trying to become more independent and integrated. Some of the observations have been positive; while, others were more hindering and negative. Families that hinder the independence and growth process are also potentially powerful because they have a role in *delaying* or *inhibiting* their family member from becoming more

independent, employed, and/or self-sufficient. Some families may also unknowingly block their family member's growth by being overprotective. Although the act may be well-intentioned, the outcome of such decisions does not always produce the best result for the family member with a disability.

Due to the complexities involved in coping with a disability and the lack of resources available in assisting families, I felt a book such as this was necessary. I wrote this book with the intention of covering a broader base of *potential family* needs. While it is not possible to cover specific needs for every single disability type or condition, this book is intended serve as a resource to be used by family members of persons with a disability and by rehabilitation and mental health counselors and professionals. In an effort to assist counselors and rehabilitation professionals in their decision-making and ethical practice, a chapter on ethical decision-making and practice has been included. In addition, each chapter ends with either a case vignette or an opportunity to apply ethical conduct to the topic or situation provided.

The content of this book was also intended to be used as a starting place for families to sort out and make sense of their experiences with self, life, other people, and society following disability. I believe this to be very important because the process of figuring out what to do following disability is often murky and extremely vague. It is my hope that readers can take the information provided and apply it to situations of childhood disability (e.g., congenital conditions), acquired disability (e.g., later onset such as TBI, SCI), or age-related disability (e.g., dementia, Alzheimer's disease), although the specific situations and needs (in some cases) may differ. It is my hope, though, that this book can be used in a "general" informative sense from which families can check out their experiences to see which ones are similar and applicable and which ones are not. Because the experience of living with a disability and being associated with it are very individualized, it is entirely possible for family members to have different perceptions and experiences than some of those provided.

In any case, learning how to cope well following a disability is very important for families and is often challenging because it is rather evident that our W*esternized nation* does not do an adequate job in helping the person with a disability or her family "figure out" how to make sense of their situation, adjust, or move on. Rather, it is a way of being that is just expected. Therefore, this book was written to provide some general information which hopefully can be applied to your situation in an attempt to help you move forward.

Generally speaking, the experience of disability and adaptation to life following disability is individualized and personal. It is just as individualized for the person with a disability as it is for the family member or family. Yet despite these differences, there are some experiences which may overlap and be similar for many people (i.e., feelings of uncertainty, shaken beliefs, search for meaning, changes in social support). Family members of persons with a disability are likely to find themselves faced with many initial questions and much uncertainty about the days and years ahead. Depending on the situation, disability type, and the relationship to your family member with a disability, different issues or concerns may surface. For instance, married or relationship partners may have questions concerning financial stability and employment, relationship roles or associated changes, and intimacy and sexual relations. Parents of a child with a disability may have questions concerning educational needs, quality of life, medical needs, and transition to adulthood and

employment. Similarly, adult children with aging parents may have needs related to personal safety, caregiving, and appropriate care. Some of the questions and concerns family members experience in these areas may overlap. Since the needs of family members are so diverse and individual, my intent in writing this book was to provide family members of persons with a disability with information and skills to assist them in their journey of learning to cope more successfully with disability and to find a better quality of life.

As you read the following chapters, feel free to use what is applicable, as some chapters and topics may resonate or be more meaningful than others. I firmly believe adjustment to and coping with disability is an *evolving* process. I say, "evolving" because where you are in your awareness, today, may be very different than where you are 5, 10, or 15 years from now. Similarly, as you evolve, your needs and perceptions will likely change. Therefore, different aspects and topics of what is included in this book may be more salient to you and your family at different points-in-time. However, as you decide to use and incorporate the information read in this book, it is my hope you will find some tools and suggestions helpful. Further, it is my hope you are able to recognize that, regardless of how you feel today, you are not alone in your journey - there are others out there who are also trying to figure out how to cope or have had to figure it out already. Your responsibility is to seek ways to help yourself feel more comfortable with your feelings, life, and situation. And above all else, I would hope that as you read this book, you can know that 'life does not have to be over' just because disability is now a part of it.

This is not a different point of a view or perspective than what many persons with disability figure out for themselves. Life is not over…….for many, it has just begun, because they have discovered a new life which some might even describe as a better life. In the end, the choice is yours: Are you going to let yourself and your happiness be defined by your circumstances or, are you going to find a way to move past this and live a well-balanced life to the best of your ability despite your life circumstances?